Legislative Assembly of Alberta

The 27th Legislature
First Session

Standing Committee
on
Health

Friday, January 30, 2009
8:40 a.m.

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Standing Committee on Health

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Standing Committee on Health

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Trevor Theman
John Pasternak

Alberta College of Pharmacists HE-207
Greg Eberhart

Faculty of Medicine and Dentistry, University of Alberta HE-211
Tom Marrie

8:40 a.m. Friday, January 30, 2009

[Mr. Horne in the chair]

The Chair: Good morning, colleagues. I'd like to call this meeting of the Standing Committee on Health to order. Before we begin, I'm just going to ask members of the committee and staff to introduce themselves. We'll start with the deputy chair, please.

Ms Pastoor: Bridget Pastoor, deputy chair, Lethbridge-East.

Dr. Sherman: Raj Sherman, Edmonton-Meadowlark.

Mr. Dallas: Good morning. Cal Dallas, Red Deer-South.

Mr. Vandermeer: Tony Vandermeer, Edmonton-Beverly-Clareview.

Mr. Bhardwaj: Naresh Bhardwaj, Edmonton-Ellerslie, here today for Jonathan Denis.

Ms Dean: Shannon Dean, Senior Parliamentary Counsel.

Dr. Massolin: Good morning. Philip Massolin, committee research co-ordinator, Legislative Assembly Office.

Ms LeBlanc: Stephanie LeBlanc, legal research officer with the Legislative Assembly Office.

Mrs. Kamuchik: Louise Kamuchik, Clerk Assistant, director of House Services. Good morning.

Ms Friesacher: Melanie Friesacher, communications consultant, Legislative Assembly Office.

Ms Notley: Rachel Notley, MLA, Edmonton-Strathcona.

Mr. Quest: Dave Quest, MLA, Strathcona.

Mr. Fawcett: Kyle Fawcett, MLA, Calgary-North Hill.

Ms Norton: Erin Norton, committee clerk.

The Chair: I'm Fred Horne, MLA for Edmonton-Rutherford and committee chair.

I have regrets this morning from Laurie Blakeman, MLA for Edmonton-Centre, who is substituting for Dr. Swann during our review of Bill 52. Ms Blakeman is under the weather this morning and not able to attend. We hope she's feeling better soon.

Just a few housekeeping items before we get started. We'll introduce our guests in a moment. For the benefit of people who haven't been here before, these microphones are operated remotely, so it's not necessary to turn them on or off. The *Hansard* staff at the back control these. The proceedings are broadcast by audiostream on the Internet, and of course our proceedings are recorded in *Hansard*. So that the sound system works smoothly, I'd just ask that if you have a BlackBerry, keep it as far away as possible from the microphone, preferably on the floor. Somewhere not on the table seems to work. We'd appreciate that.

Before we get into the agenda, I just wanted to make a comment about the materials that were circulated prior to the meeting. The materials that are being posted – and I recognize that they're coming to you in some cases just a day or two before the meeting – represent advance copies of the materials that are going to be presented to the committee during the series of presentations. While I understand it's very helpful to all of us to try to take a look at them in advance, I just want to stress that it's not critical to have read those in order to be able to understand the presentations and participate in the discussion.

Normally, we try to have materials posted about a week before the meeting, but in this particular case we scheduled three meetings of the committee on fairly short notice, and the result was that the invitations to the presenters also went out on shorter notice than would normally be the case. I've asked the clerk to ensure that anything that we have received now for next Wednesday's meeting is posted today. I don't believe we have all of it in yet. We're still waiting for some presenters to forward the material. I just wanted to assure you that we are posting it as we receive it.

We'll move to item 3, and I'll ask for a motion to approve the minutes of the last meeting. Moved by Mr. Quest. Discussion? Corrections? Changes? Those in favour? Opposed, if any? That's carried.

Just before we move on, I'll ask if we have Mr. Olson on the line. Good morning, Mr. Olson.

Mr. Olson: Good morning. My apologies, Mr. Chair, for being late and having to leave early as well.

The Chair: Not a problem. Mr. Olson, MLA for Wetaskiwin-Camrose, has joined us by teleconference.

Mr. Olson: Good morning, everybody.

The Chair: Item 2. I'm sorry; we did these in reverse order. We should approve the agenda. Can I have a motion to approve the agenda, please? Mr. Fawcett. Any discussion? Changes? Those in favour? Opposed, if any? Carried.

The next item is a communications update. You'll recall that at the last meeting we had a discussion about placing an advertisement for public input. We agreed that given the situation with this particular bill, we would be holding the advertisement until likely February 13, on or about that date, in order to provide an opportunity for a motion in the House to reinstate this bill as it will be prorogued on February 9. We're still working to that timeline. Again, the reason is that we would expect the bill to come back with a change in name, certainly the year will change, and as well it may receive a new number.

Just for the information of the committee, I've made the necessary inquiries and have requested both early notice on the Order Paper for this and that the government make the necessary motion as soon as the next session begins, on February 10, so we should be in good shape to proceed with the ad on or around February 13.

A draft of the advertisement was circulated to the committee in advance of today's meeting, and I'd like to just take a moment to review that and ask for committee approval on it so that we're positioned to move on the 13th of February. Has everyone had a chance to review the ad? As we discussed, we went with essentially the same text and format as the advertisement we ran in our review of Bill 24 in the current session. We did have a discussion and made a decision at the last meeting to place the ad in both daily and weekly newspapers for purposes of the review of this bill.

Mr. Dallas: Mr. Chairman, is the ad in our information package to the scale that it would appear in a newspaper, or is this an enlarged version?

The Chair: I'll ask Ms Friesacher to answer that.

Ms Friesacher: I'm not sure. Yeah, some people have enlarged it. The actual size is 5.5 by 5 inches. It's an average-size ad.

Mr. Dallas: Okay. Thank you.

The Chair: Ms Pastoor.

Ms Pastoor: Yes. This will all be on the Net as well?

Ms Friesacher: Correct. It will be referred to our website, the Standing Committee on Health.

Ms Pastoor: Thank you.

The Chair: If there's no other discussion, then, I'd like to ask for a motion that

> the committee authorize the chair and the deputy chair to approve the advertisement for public input as presented on behalf of the committee and allow us to authorize placement of the advertisement once the bill has been reinstated by the Assembly.

Mr. Dallas. Any discussion? Further questions? Those in favour? Opposed? That's carried. Okay. Thank you very much.

I'd like to just ask Melanie at this point if she has any other items for the committee with respect to communications.

Ms Friesacher: Thank you, Mr. Chair. There's also a communications draft strategic plan, that was posted, and it basically outlines key messages that were developed based on what's been focused on in the meetings so far. The key messages are also included in this advertisement and will be used throughout campaigns.

Something else just to be aware of is media relations. News releases and advisories will be issued sort of at critical periods, so when we start the public hearings, that sort of thing, and we would advise that the chair of the committee and the deputy chair also be authorized to work with communications on finalizing those. Essentially, for public hearings, if we choose to hold public hearings, we can also develop a communications strategy surrounding that, but we have a framework already with the website and advertisement in place, so we're just going to carry on as per the previous bill.

The Chair: Thank you.

Are there any questions for Melanie? I'm not going to propose that we formally approve the plan at this meeting. It's kind of been our practice to bring forward recommendations around advertising and media notices and so on as they've come along. Of course, we don't have any public hearings scheduled at this point on the bill. Our written submissions won't be coming in until later in March. Any questions? I think it certainly provides a framework for us to work from and does a good job of articulating the purpose of the bill and the activities of the committee and so on.

Okay. Seeing none, any other comments, Melanie?

8:50

Ms Friesacher: No.

The Chair: Okay. Thank you very much for your work on that. It's appreciated.

The other thing I would mention is that we had a discussion at the last meeting about research requirements for the committee. One of the pieces was posted this morning. The cross-jurisdictional comparison has been posted on the committee website. We are not going to be taken through that at this meeting. We'll have an opportunity at a future meeting for research staff to present the materials to us and answer questions. I just wanted to draw that to your attention. Any other discussion on that? I don't think I'll go back through the items that we listed. They're there in the transcript and in the minutes for your review.

Okay. Seeing none, then, we'll move into our scheduled presentations. I'd like to begin this morning by welcoming representatives of the Health Quality Council of Alberta: Dr. John Cowell, chief executive officer, and Ms Charlene McBrien-Morrison, surveys and reporting lead. Thank you very much, Dr. Cowell and Ms McBrien-Morrison, for appearing before the committee. It's a pleasure to have you here. I understand that some materials are being circulated now that you're going to take us through in the presentation, so we'll just give the clerk a moment to do that.

Dr. Cowell, if you'd like to proceed with some introductory comments. Essentially, though, the way we try to do this is that we allocate approximately 30 minutes per presentation and try to divide that between about 15 for the formal presentation and leave at least 15 minutes for questions and discussion with the committee. With that, I'll just turn it over to you, and we'll get moving.

Health Quality Council of Alberta

Dr. Cowell: Thank you, Fred. I appreciate the opportunity to be here, and as you have said, I've brought along my colleague Charlene. When it comes to the Q and A section, either one of us will attempt to respond to any of the questions.

What you're getting is a short fact sheet hitting the highlights of what we would like to say today. In addition, we thought that you would also like to have an additional copy of what's turning out to be a very successful advisory, really, that we've sent out to virtually all the citizens of Alberta as it relates to their ability to communicate effectively with their care providers in the system. At the end, if we have time, I'd like to come back to that. Each and every one of you received a copy of this, and it's our plan to send you more because of the overwhelmingly positive response we're getting from the public.

That said, I know that some of you know something about us and others may not know much about us, so we thought that at the very beginning we'd position our comments in relation to our own regulation. The Health Quality Council of Alberta was established as a provincial health board back in 2006 under the Regional Health Authorities Act, and we have our own regulation, 130/2006, the Health Quality Council of Alberta regulation. With the consolidation into Alberta Health Services I guess there are only two of us left: a great big one and a tiny little one like us. There are no plans for us to be merged into the big Alberta Health Services. We remain a stand-alone, external monitoring agency, and we'll just carry on working with the same players, only rearranged in a different organizational structure.

The other thing to state is that we have a province-wide relationship. It isn't just with the things that Alberta Health Services deals with. We also have a relationship with all the care providers both in the community as well as within Alberta Health Services, and our regulations focus that. In the objects of the quality council our mandate is "to promote and improve patient safety and health service quality on a province-wide basis." Spelled out in there are exactly how and what we should be looking at.

In our regulations health service quality means the general quality of health services as measured by these six dimensions of quality:

accessibility, acceptability, appropriateness, efficiency, and effectiveness. Patient safety means "the activities, strategies and mechanisms to avoid or mitigate health risks to users of the health care system." We have set up a system whereby we really adhere to these definitions. In the two years since we've been in formation, we are now at the position of measuring and evaluating against these dimensions. I won't dwell on that today, but much of the material you'll see flowing from us will come back constantly to these six measurable dimensions of quality.

The objects also go on to say that we are to undertake the following activities:

(a) measure, monitor and assess patient safety and health service quality;
(b) identify effective practices and make recommendations for the improvement . . .
(c) assist in the implementation and evaluation of strategies designed to improve patient safety and health service quality;
(d) survey Albertans on their experience and satisfaction with patient safety and health service quality.

The regulations go on to lay out how we should co-ordinate with the professions, including academic medicine and academic nursing and so on.

In that context, when we were invited to come to the committee, we asked ourselves the following question: do the amendments presented in Bill 52 impact the quality and safety of the Alberta health system? Based on that question that we asked ourselves, we decided to focus in the short time we're with you today on two parts of your amendments: 5.1, the Alberta electronic health record, and 6.1, the health information repository concept.

Starting with part 5.1, the electronic health record, the Health Quality Council has been conducting Satisfaction with Health Care Services surveys since 2003. We've done four of them. We've released three, and we're just in the final analysis of our fourth. These are very broad-based, population-based surveys. We get at a wide range of questions. We poll throughout the province. We get a very large sample size so that the margin of error is as low as we can possibly make it. These are designed to truly get at what Albertans really think about their experience, their perception of the system. It was from these surveys that we felt our most powerful statement should come to you.

We've also done groundbreaking surveys in terms of emergency services and the satisfaction with those throughout the province. In other words, we've surveyed every single emergency department. Now we're at the users of the surveys, not just the general population. As you may know, we've just released a huge baseline survey of long-term care from the satisfaction of the residents and their families. In each and every one of these surveys we are getting a consistent message from the population. They identify always, in every one of our surveys, that the co-ordination of care and communication between care providers and patients in the system is flawed. They give us example after example of this.

Common examples are that critical and routine clinical information does not always pass or isn't available between the various physicians or between physicians and hospital locations. We know that when there's a breakdown in this information flow, say from a primary care provider to the emergency department or from the emergency department back into a continuing care setting, medication error occurs. The fact that laboratory studies may go astray means that there's a possibility that the care path will not act in a timely fashion or an appropriate fashion. We know that something needs to be in place to correct this. We believe that the electronic health record will dramatically improve co-ordination of care and close some of those critical communication gaps between providers, patients, and institutions.

9:00

Therefore, when we look at the Health Information Act amendments, we would state that we would strongly support those amendments that are designed to enable the appropriate use of the EHR. We believe that the consistent use of the Alberta electronic health record in day-to-day clinical care will have a positive impact on all six dimensions that we study as it relates to quality and safety. We have the capacity to monitor this, and we will be monitoring it through our analysis of clinical outcome data.

We didn't get into the various elements of section 56.1 in relation to authorized users, but I would state that we feel that the definition of an authorized custodian to us appears appropriate. As an example, we feel very comfortable that we are not an authorized custodian. We feel that we can conduct our work quite adequately without being named as an authorized custodian. We would say the same about researchers as well. We do not see why anyone would need to other than a clinical care provider who would use the system on a day-to-day basis for clinical care purposes. We believe that those individuals within those institutions are the ones that should be designated, as the amendment is written, as authorized custodians.

We are a custodian in the larger sense, and if our work leads us to the point where we need to, we could always become an affiliate custodian if it was appropriate and we had gone through the appropriate privacy hoops through the privacy impact assessment process.

Moving on to part 6.1, the health information repository. It's a bit hard for us to fully comprehend how that would operate because the act is as yet just positioning the concept, as we see it, of health information repositories, but we would state that appropriate access to health information is necessary for health researchers to conduct research on questions of health service quality and patient safety. When we go to the literature – and we do regularly – there is not a great depth of available peer-reviewed research done specific to the topics of health service quality and patient safety. There is an immense amount of material out there, but what we're hoping to see from appropriate access to the health information is more specific and targeted research in this area.

Now, we don't feel particularly qualified to speak directly to the privacy issues and how the health information repository would work, but we do feel that we could speak to one of our dimensions of quality, and that is acceptability. We define acceptability as health services that are respectful and responsive to user needs, preferences, and expectations. Based on this dimension of quality, we believe that should health information repositories become a reality, an individual's health record should only be disclosed to researchers in a manner that protects the privacy and wishes of the individual.

That said, there will be analyses done by health researchers. They are going to look at trends. They are going to look at groups. They are going to look at the way in which disease is manifested and handled in whatever research question they're being asked. So mechanisms are going to have to be designed that protect individuals and their own record in that process yet still enable the researchers to conduct appropriate clinical outcome research.

In the short time allotted, we thought that those would be the two most important areas for us to comment on. We would be, of course, very happy to get into some questions around this.

The Chair: Thank you very much, Dr. Cowell.

Questions or comments from committee members?

Ms Notley: Sure, if no one else is jumping in.

The Chair: Ms Notley, followed by the chair.

Ms Notley: Thank you for that presentation. Just a couple of quick questions, really. You mentioned that you do analyses of clinical outcome data. I'm just wondering: do you have any information in your custody at this point relating to improvements or changes post the introduction of this legislation in the first place in terms of whether or not you've seen improvements with respect to clinical outcomes since – whenever it was – 2001, I believe? Have you had an opportunity to do that kind of work?

Ms McBrien-Morrison: Just so I'm clear, Rachel, you're asking: have we done this kind of work since the health amendment act itself came in?

Dr. Cowell: The Health Information Act.

Ms Notley: Yes.

Ms McBrien-Morrison: Yes, we have.

Ms Notley: I'm just wondering if we can . . .

Dr. Cowell: Maybe I should answer. We have access to the provincial database in an anonymized fashion, and we have begun to analyze the available database. In order for us to do that, we went through a very rigorous privacy impact assessment process and worked very, very closely with the Privacy Commissioner.

Ms McBrien-Morrison: As well as the ministry.

Dr. Cowell: As well as the ministry.

It was a lengthy, detailed, careful process, finally at the point of completion and access. It's not easy work, and we want to be careful that we understand the questions we're pursuing. Probably within the next six months we will be in a position to release our first report on elements of that database that we've decided to report back on: clinical outcomes. So it's coming, but we have as yet not published.

Our only published work so far is our extensive survey work, and that is from our own database, one that we've established, well, since '03, I guess. That one, by the way, is completely anonymous and fully open to the public.

Ms Notley: Could I ask one more question, and then I'll be done? Really.

Just on a slightly different topic, in terms of your overall mandate with respect to assessing and examining the quality of patient safety and health services quality provision, however exactly it was put, would, let's say, a breach of confidentiality experienced by a patient ever factor into what you're analyzing? Would there ever be a point at which that incident would be something you'd observe just in terms of your overall mandate? It would make perfect sense if it wouldn't. Don't get me wrong; I'm not suggesting it should. I'm just curious as to whether that ever is something that you do examine.

Dr. Cowell: To me that would be a new idea.

Ms McBrien-Morrison: Yeah. Right. It certainly comes under other agencies' purview more than it does ours.

Ms Notley: Absolutely. I could see where it might. I just wanted to ask.

Dr. Cowell: The flip side has come under our interest. That is that our study showed very early on that the disclosing of harm to patients was not occurring broadly or correctly throughout the province where they felt harm had occurred or they didn't know that harm had occurred, and they have a right to know.

So that led us to work broadly with the professions as well as the regional health authorities to put forward the Alberta disclosure framework. This is a framework on how to disclose harm, do it appropriately in a timely fashion. We're pretty proud of that because Alberta is the first of all the provinces to come out with something like this, and it has been in play now for two years. We're about to study whether that has made a difference. Prior to that happening, we knew that disclosure was not happening as frequently as possible. Soon we're going to know whether that has changed through our survey work.

Ms Notley: Thank you.

Dr. Cowell: You're welcome.

The Chair: Thank you.

Dr. Cowell, I just wanted to pursue a comment you made earlier. You indicated that you did not believe it would be necessary for a researcher or, I guess, a research organization to be designated as a custodian under this act.

Dr. Cowell: Authorized custodian.

Ms McBrien-Morrison: As it pertains to 5.1.

Dr. Cowell: It was a very precise comment: an authorized custodian. I think your definition is under 56.1 in part 5.1 of the act.

The Chair: Could you just elaborate on why that's your belief?

Dr. Cowell: Well, we believe that the electronic health record is designed for clinical care, day-to-day clinical care, where a specific person's record is available appropriately to the clinical intervenor in sort of like a real-time sense. We can't visualize why either we or any other researcher would ever need to know and have direct access in that same way a clinician would have for research on clinical outcomes.

9:10

The Chair: I would agree with you, but if other organizations – and I understand your access to health information is by special provision because of the nature of your organization and your standing under law. Aggregate, nonidentifying information provided to universities or other research organizations for the purpose of, for lack of a better example, say, population health outcome research that's directly connected to improvements in the health care delivery system: would you not agree that those organizations would require access to data?

Dr. Cowell: Totally. I would completely agree, and Charlene will elaborate. In that sense, yes.

Ms McBrien-Morrison: It's more a definition. Direct access to the Alberta electronic health record, no, but the appropriate disclosure of information from that to them for research purposes would be appropriate.

The Chair: It's my understanding that one of the purposes of the bill is to permit that access by having the capacity to designate such organizations as authorized custodians but only for the purpose of aggregate, nonidentifying data.

Dr. Cowell: Our interpretation of the act may be flawed. We saw custodians differently from authorized custodians. Custodians would have certain rights; authorized custodians would have enhanced rights. Authorized custodian, unless we've interpreted it incorrectly, applies to us. These were individuals or individuals within institutions that had direct day-to-day requirement to use in a real-time sense the electronic health record. They could go in and see Fred Horne's results right now because Fred Horne needs treatment, but would a researcher standing back, exploring a question of clinical outcome, need to know that that was Fred Horne's record, or would they just need to know that it was somebody's record that looked like that; in other words, an anonymized fashion?

Now, I'm not here to speak on behalf of researchers. We just were commenting, standing back, trying to think from the point of view of improving quality and safety: would someone actually need to go in and know everybody's individual names? We couldn't find a reason why they would need to do that that would harm their ability to conduct pretty profound and useful research. Now, it's not inconceivable that a researcher could have a different argument that would be persuasive, but that was just our take on it. Certainly, when we explored whether we needed it, we said, "No, we don't need it." We think we'll get a very specific and useful analysis and be able to bring forward very important analysis to the policymakers and service providers and the general public without having that day-to-day access and use of the electronic health record.

We wanted to be sure that we were presenting our argument carefully to you because we strongly believe the electronic health record is vital and the consistent and universal use of it is very vital for clinical care to improve co-ordination. Gaps are occurring now because paper files don't flow properly, paper disappears in places it shouldn't go, and the timeliness of the co-ordination of care is seriously hampered.

The Chair: Thank you very much. It's very helpful.

Ms Pastoor.

Ms Pastoor: Thank you, Mr. Chair. Dr. Cowell, this may be a bit off on a tangent, but you spoke about disclosure of harm to patients.

Dr. Cowell: Yes.

Ms Pastoor: I'd like your definition because to me there's a big difference between harm to patients via treatment or via care, and I see that you've used the word "care," where I probably would have used "treatment." Day clinical care to me is treatment. My background is long-term care. While someone may be in the hospital and receive good treatment there, they are often sent home too early, and it's the care part that they don't – to me that's part of the care, where you have to look at what's going to happen to them, not the treatment part. Do you understand what I'm saying?

Dr. Cowell: Sure, I do.

Ms Pastoor: And that disclosure part of it.

Dr. Cowell: I'll just say it, and then jump in, Charlene. We see care as the generic term to use. It includes treatment. It includes the human relations around that treatment, like the interface between the care provider and the user. Our thinking goes there because we believe acceptability is an important aspect of high-quality care. When we talk about appropriateness and effectiveness, we're talking about the relevance of treatment, whether it was the care you needed or the treatment you needed and that you got. Did I need the treatment I got, and did I get the treatment I needed? When we talk about efficiency and effectiveness, we're talking about: was that from a scientific and a clinical practice guideline point of view the correct treatment for that clinical problem? We use these as bookend ideas but always embedded in the idea: was that acceptable?

Now, care can also go beyond even that to prevention. It could be accommodation. It could be nutrition. I mean, it could be things beyond the clinical notion of, say, a specific medical intervention. When we get into disclosure of harm, our disclosure is really built on the idea of whether it was preventable or not preventable. If something harmful occurred, the patient has a right to know what that was like and how it happened. This isn't about naming blame or shame or anything. This is just that you have a right to know.

When we surveyed the population – and we have very rich data on this – they have an absolute expectation that they will be told because it's based on a trust relationship between the individual user and the system. If they don't think they're being told yet they know that they should be told, then both sides get very tense. So that's why we came forward with, "Well, this is how you do it" without saying, "Oh, my God, I just did a terrible error, and it's all my fault." It's not about assigning blame. It's assigning truth to an interaction, and later on you'll get into it.

We didn't dwell on it today, but we also have power under the act to conduct inquiries. You may know that we did the large inquiry into the east-central infection prevention control and sterilization failure. We've done a number of inquiries that get at issues like that. Inevitably, things like disclosure play into those situations.

Ms Pastoor: Thank you. I think, again because of what comes through my office and probably part of my background, we're both speaking at different levels. You really are doing the big picture, and I'm trying to do the little guy on the bottom that's in some way been harmed and would probably think that they were harmed under the care side rather than the treatment side. Do you actually differentiate between those two, or is it sort of one package in that big picture that you look at?

Dr. Cowell: For us it's one package.

Ms McBrien-Morrison: I would agree. Absolutely.

Dr. Cowell: Charlene comes from your world, long-term care.

Ms McBrien-Morrison: I would absolutely agree. Our definition is broader, includes all of those dimensions, if you like, whether it be care, treatment, clinical interventions, et cetera. It's the whole. As we used to speak to, there are sort of the clinical interventions even in long-term care, but then there's that whole hospitality in care side that's as critical to that. We think of it in the broad sense, absolutely, and as it pertains to disclosure of harm as well, yes.

Ms Pastoor: Thank you.

The Chair: Thank you.

Dr. Sherman.

Dr. Sherman: Thank you, Mr. Chair. Dr. Cowell and Charlene, thank you for appearing before the committee today.

As health care providers patients tell us very confidential, vital, intimate information, and as someone who has to make decisions, it's absolutely essential that we have the ability to get information to deliver the proper care to patients. It is absolutely essential as well that as individuals the most personal and vulnerable information is protected for the patient.

In going forward, the electronic health care record, I believe, will help improve the efficiency of the system, help deliver better care and safer care, but if the privacy of the patient isn't protected, patients may not tell their physicians intimate details if they're not confident that their information will be protected. If they tell the information, the health care provider, if they're not confident that the information is protected, may not enter certain information onto the electronic health data. So until we are confident about the security of the EMRs and EHRs, it's vitally important that we err on the side of privacy and ensure that we have a system that can protect the patient. As the Health Quality Council part of your mandate is to look at the quality of care, my question to you: have you studied the safety of the electronic health record that we currently use?

9:20

Dr. Cowell: That's a great question. We have looked at the literature on it, and there are some concerns that, in fact, when security breaks down, this could be an issue. There is some literature – and I can't quote it directly – that, in fact, if the electronic health record is not implemented correctly, it can have a negative impact on patient safety. We were using that very powerful word "appropriate" implementation of the electronic health record because conceptually it's just a no-brainer that an effective, highly integrated, secure electronic health record will inevitably improve clinical care, and there are examples out there. Intermountain Health from Salt Lake City would be an example I would show where these are successfully implemented and where there is measurable improvement.

But you're absolutely right. There are risks and there are dangers, so it needs to be done in a way that is absolutely secure, as secure as financial information is, and sometimes even that breaks down. This is intimate, important information that is specific to individuals. That's why we've taken that other – maybe some might say contrarian – view on health information repositories. We believe strongly in that acceptability dimension of quality. We have a right to privacy, and as you point out, people might hold back.

In fact, that's a great segue to this. I sure hope every one of you will take a moment to read this thing called It's Okay to Ask. This is directly – well, it's in context with the issues that you're dealing with. We worked with the professions as well as the folks out there, the citizens of Alberta: how do we improve the relationship between you and your provider in the institution? What we found is that health literacy is very low in this country. Just your average person doesn't even know how to describe themselves. They feel intimidated sometimes to describe intimate stuff. Fifty-five per cent are deemed to have low health literacy because they don't have the speaking or listening skills to interface with their provider. They don't know how to organize their thinking to get the best out of a health care encounter.

With lots of collaborators within the province we put this thing together. We've distributed over 300,000 copies, and we're going to do another run because it's just turning out to be wildly popular. Inside it we've put a cutaway template, and people should make copies of this so that before you get in to see your care provider, you figure out how to describe what it is you want them to think about, the top five questions you should ask before you leave so that you don't leave misunderstanding, and also your list of medications. This will dramatically improve what you say and how you say it to your care provider. I think that in the end this could be traced to improving the quality of the information that's arriving within the electronic health record because the electronic health record ultimately will capture what people are saying to the providers and will be embedded in the record. I mean, we didn't design that for that purpose, but I can trace it that way.

Dr. Sherman: Just a follow-up: can you comment on Bill 52 and what your opinions are? Does it provide us as policy-makers with reassurance that privacy will be protected so that we can utilize the positive benefits of the health record?

Dr. Cowell: Well, the only comment that we were able to make today, based on our analysis in just looking at it – and we want to be sure that we don't speak beyond what we are qualified to speak to. That's why we made the specific comment about authorized custodians. Our take on the way in which that amendment is written: it looks correct to us. It would appear to restrict the use of the electronic health record to clinical users, and we would agree with that. So I think that to that end it would say to us that the electronic health record is there for clinical users. Now, ultimately that electronic health record will have to be mined for aggregate information and trend lines and outcomes for researchers, but would someone like us or researchers need to have sort of day-to-day access to it? We see that the privacy protection against that is necessary. Maybe I'll phrase it like that.

Dr. Sherman: Thank you.

The Chair: Okay. Thank you.

We have time for one last question. Ms Pastoor, please.

Ms Pastoor: Thank you very much, Mr. Chair. Dr. Cowell, I'd just like to go back to something that you mentioned about Salt Lake City. Were those state numbers or just the city numbers?

Dr. Cowell: No. Intermountain Health is a self-contained health system within the state of Utah. It happens to be headquartered in Salt Lake City. It's a not-for-profit health system, really in some ways a mini version of ours. They have – I don't know – maybe a dozen hospitals in it, umpteen emergency departments. I think they have 2,000 primary care providers. It's fully integrated. I believe it had its roots at one point in a religious order, but it's now a not-for-profit institution much like the Mayo.

They have for many years been working on and developing an electronic health record. I think it's decades old. It's the envy of most places when you want to look at a high-functioning electronic health record. So we know that they exist. They have done studies on how an electronic health record improves the quality of care and patient safety, and it is dramatic. That's why we feel confident to say that co-ordination of care will be improved with such a system.

Ms Pastoor: I'm not clear. Do people subscribe into Intermountain, or does it just do it for the whole state?

Dr. Cowell: Not for the whole state.

Ms Pastoor: Just for those who subscribe to that particular organization?

Dr. Cowell: Yes, you can subscribe, but also, because it's a not-for-profit, even people without some form of U.S. insurance can walk in the doors and would be seen in a charitable sense.

Ms Pastoor: Okay. If I could just do a follow-up on your brochure. What level of education do you need to be able to read this and understand it? Also, in how many other languages has it been put out?

Dr. Cowell: It's our first attempt at, if you will, social marketing in this way. Well, maybe I should say that it's our second. We did another one on medication safety. We write to about a grade 8 or 9 level. We fully recognize that this is not going to get to the hard-to-reach. It's not going to get to the functionally illiterate. But we felt we just had to start somewhere. This is our first foray out there. It's astonishing to me. Even yesterday we were at our own board of directors, and our chair was mentioning that a professor he knew – I don't know if it was in medicine – was having difficulty even himself articulating how to describe his family's problems, and darned if he wasn't ripping this thing out and making his notes right on it.

You can go right on our website and download these templates. What we're trying to do is make it easy, just give a kind of framework for thinking for ordinary people to be better team members, if you will, in their own care. The physicians are calling for these things. They're putting them in their offices. Pharmacists are calling for it. It's just: wow, we're going to do more of this. We think we need to do more of this.

Ms Pastoor: Well, I'm sure the physicians are more than happy to have them quote this rather than the Internet. Most patients can go in and tell the doctor what's wrong with them because they saw it on the Internet.

Dr. Cowell: You know what? We thought that, too. Very few people, actually, a small number of very vocal people, know how to use the Internet and are smart. We're not saying that you've got to be as smart as a doctor. We're just saying: organize your thinking.

Ms McBrien-Morrison: There are plans for us to explore how we can get to those harder-to-reach populations, et cetera, so that we can reach a broader audience, absolutely.

Dr. Cowell: Absolutely.

The Chair: Well, Dr. Cowell, Ms McBrien-Morrison, on behalf of the committee thank you very much. You've been very helpful. We appreciate your participation in the meeting and any information you've provided.

Dr. Cowell: Thank you.

Ms McBrien-Morrison: Thank you.

The Chair: We'll just pause for a few seconds while we reposition the table at the other end and our next group of presenters gets settled.

Mr. Olson: Mr. Chair, I'm going to have to leave here pretty quickly. I'm just wondering whether I should leave now or whether I can just quietly hang up without any disruption.

9:30

The Chair: I think you're in a position to make the decision as you wish, Verlyn. It's not a problem to hang up the phone.

Mr. Olson: Maybe I'll just hang in for another 10 minutes or so.

The Chair: Yeah. There's a signal here that tells us when you've disconnected.

Mr. Olson: Okay. Thank you.

The Chair: Thanks.

Colleagues, I think we'll proceed. If I can call the meeting back to order, our next presenters are from the College of Physicians and Surgeons of Alberta. I'd like to welcome Dr. Trevor Theman, registrar of the college. Welcome, Dr. Theman. It's nice to have you and Mr. John Swiniarski here. I hope I pronounced that correctly. Please correct me if I haven't. Mr. Swiniarski, you're the assistant registrar of the college. That's my understanding. Thank you very much for being here.

We'll just quickly go around the table. I'd like to have you meet the committee directly. We'll begin with the deputy chair.

Ms Pastoor: Hi. I'm Deputy Chair Bridget Pastoor, Lethbridge-East.

Dr. Sherman: Hello. Raj Sherman, Edmonton-Meadowlark.

Mr. Dallas: Good morning. Cal Dallas, Red Deer-South.

Mr. Vandermeer: Tony Vandermeer, Edmonton-Beverly-Clareview.

Mr. Bhardwaj: Thank you. Naresh Bhardwaj, Edmonton-Ellerslie, sitting in today for Jonathan Denis.

Ms Notley: Rachel Notley, MLA, Edmonton-Strathcona.

Mr. Quest: Dave Quest, MLA, Strathcona.

Mr. Fawcett: Kyle Fawcett, MLA, Calgary-North Hill.

The Chair: I'm Fred Horne, MLA for Edmonton-Rutherford and committee chair.

On the phone we have Verlyn Olson, who's the MLA for Wetaskiwin-Camrose.

Mr. Olson: Good morning.

The Chair: Dr. Theman, what we like to do is keep this to roughly 30 minutes or so. We'd ask you to make any introductory comments for up to the first 15 minutes and then leave us some time for questions and dialogue with you following the presentation.

Dr. Theman: Very good.

The Chair: Please proceed.

College of Physicians and Surgeons of Alberta

Dr. Theman: Thank you, Mr. Horne and members of the committee. On behalf of the Council of the College of Physicians and Surgeons of Alberta I'd like to thank you for the opportunity to present in

public our views and suggestions about Bill 52, amendments to the Health Information Act.

As Mr. Horne has indicated, my name is Trevor Theman. I'm the registrar, and I'm accompanied here – I have to explain. Mr. Swiniarski was going to attend with us. In fact, this is Dr. John Pasternak. He's the president of the council of the college. Just to make the security easier, we snuck him in under Mr. Swiniarski's name.

The Chair: Your name tag is a little misleading.

Dr. Pasternak: It is. Sorry about that.

The Chair: Thank you.

Dr. Theman: This past summer we did a survey of elected officials – and I thank those who participated – to try and learn what level of understanding Members of the Legislative Assembly have with respect to our organization. As 80 per cent of respondents thought that we negotiate fees on behalf of physicians, I thought I'd take a couple of minutes to explain who we are.

The College of Physicians and Surgeons is the regulator of the practice of medicine in Alberta. We operate under legislation, and we fulfill that mandate by registering physicians. We set standards of practice, and we administer a complaints and discipline process. We also operate a number of other programs, one of which I'm going to touch on today that's called the triplicate prescription program.

Our mission is to serve the public and guide the medical profession. While physicians are our members and they support our work through their annual licensing fees, our moral owners are the public of Alberta. In fact, we do not negotiate fees on behalf of physicians. That's the role of the Alberta Medical Association. Our members, physicians, have been custodians under the Health Information Act since its inception, and as such we have considerable experience as the regulator of the act as it applies to the practice of medicine and, specifically, the doctor-patient relationship. It's that experience that informs our position on these proposed amendments.

The letter of invitation to attend and present identified five specific areas, or principles, within these amendments. I'll speak initially to a couple of the simpler ones and the ones that we support. We support the expansion of the Health Information Act to include all health services, not just those funded by the public health system. As a custodian having some personal information covered by the authority of HIA and some information ruled by other privacy legislation is confusing and administratively difficult. We see no reason to have different rules or legislative regimes for health information based on who pays for it. As such, we support that amendment.

We also support the amendment that would allow the Information and Privacy Commissioner to enter into information-sharing agreements with commissioners from other provinces to co-ordinate activities and handle complaints that may involve multiple jurisdictions. This just makes sense to us.

Now for those things that may be more controversial. I'm first going to speak with respect to the electronic health record, the EHR, or Netcare. While we support the need for a legislative framework for Alberta Netcare and other electronic health record systems, we are disturbed by some of the supporting amendments that in our view diminish the individual Albertan's control over the sharing and use of his or her personal health information. In that we echo the concerns raised by Alberta's Information and Privacy Commissioner, Mr. Frank Work, who in his news release of December 1 commented that "the present amendment will remove the last measure of control individuals have over their health information and no justification has been offered. We cannot support this." Those are Mr. Work's words.

The amendments contemplate that the sharing of information between authorized custodians within Netcare would become a use, as defined by the legislation, rather than a disclosure. Doing so removes the current requirement by custodians to consider the expressed wishes of an individual when deciding how much information to disclose and the requirement that a custodian maintain a log of disclosure. If we truly believe that individual Albertans have legal and moral autonomy over their bodies, then we should accept that individuals have legal rights over their private and personal health information, and the HIA should respect and support those rights.

Consistent with the goals of the Health Information Act we acknowledge the need to balance individual rights to control personal health information with the legitimate goal, on the other hand, of enabling access and sharing of personal information not only to facilitate the care and treatment of an individual but also to assist in the management of the health system. The HIA as currently written achieves a reasonable balance. However, in our view these amendments would tip the balance away from allowing individuals to control how their information is shared and used. As written, we cannot support the amendments around Netcare in their current form.

Along the same lines, we're very concerned about section 56.3(1), which authorizes the Minister of Health and Wellness to require a custodian to make information under its control accessible to authorized custodians via the EHR. Physicians acting ethically and probably other custodians as well will have a lot of difficulty with this requirement depending, of course, on what the minister may decide must be shared and depending on the wishes of individual patients. One possible effect of this might be for physicians and patients in that office setting to agree not to enter certain health information into the physician's record, whether that's in paper form or electronic form, thereby preventing its disclosure to Netcare. Such workarounds cannot be in the interest either of patients or of the health system.

9:40

Physicians and patients will have grave concerns about possible secondary uses of information made available to Netcare and other electronic health records. It may be okay to post certain information – so, for example, my HIV status or my history of mental illness – to Netcare for my future treatment, but it would not be okay if an insurance company or a future employer were able to gain access to that information without my consent. The whole question of secondary use of such information is terribly important. In our view, then, to safeguard how personal information is used by secondary sources, we strongly recommend the creation of a governance structure for Netcare and other electronic health records with broad public representation and, ideally, custodian representation – you'll see in our written submission that we think it's the public representation that's most important – as one method by which rules and principles may be established around the secondary uses of health information in a manner that would be acceptable, we think, to the public and to the health professions.

Turning now to data repositories, we support the need for a legislative framework for health information repositories. Indeed, we're supportive of the creation and use of health information repositories for research and other purposes. Currently, our organization maintains a specific database of prescribing information

for a group of drugs that are subject to abuse. This database is called the triplicate prescription program. It's authorized by the HIA, and the database is used by pharmacists, dentists, and physicians and their respective regulators.

While it's primarily a database that provides information to health care providers like physicians, for example, about a patient's individual prescribing history with respect to these specific drugs, it also provides us as the regulator a window into medical practice, so it is very specific. It's individually identifying information both about physicians and about individual patients so that one can look at what a particular patient has been prescribed and one can look at the profile of a physician prescriber. Sometimes if that information raises a series of red flags or questions, we will then seek information from the physician, and depending on what we get back from the physician, we may request a greater, in-depth review of what that physician is doing in practice. That could be up to and including education and a further monitoring of practice. So while this is a limited group of drugs, it provides us a valuable window into physician prescribing and, therefore, into physician practice.

Now, in time this program, the triplicate program, will be replaced by the pharmaceutical information network, and that will house dispensing and prescribing information on all drugs. This will be a much more powerful tool to monitor what physicians and pharmacists and others are doing in their practices.

This leads to our support for a legislative framework for health information repositories like this not only for research purposes, which we support, but for regulation of the health professions as well. We're very excited about the potential to use databases like the pharmaceutical information network to monitor and provide feedback to physicians in much more real time than we're currently able to do. Based on our experience we believe this type of approach has great potential to improve medical practice; that is, to bring those physician outliers into line with best practices, thus providing higher quality care to patients, achieving better health outcomes, and ideally saving money for the health system. As a policy committee I ask you to ensure that the legislative framework facilitates not only research but also regulation of the health professions.

I just want to touch on a couple of things here in closing. While we understand the rationale for removing reference to health service providers' information from the HIA, we also believe that some health service provider information should be protected from secondary uses. There are currently companies that buy physician prescribing information from pharmacies and pharmacists, and they sell that information to major pharmaceutical companies, who then use the information to identify prescribing practices of individual physicians and to market their drugs. That use of prescribing information has no benefit, in our view, to patients or prescribers. However, it is powerful information for marketing purposes for major pharmaceutical companies. It's clearly not in the public interest and, in our view, should be stopped. While we support and understand the amendment in HIA to focus just on personal information of patients, we also ask you as the Standing Committee on Health to consider some safeguards to address this particular issue.

Finally, we understand from the department that at the time that the act in its amended form is proclaimed there will be regulations proclaimed as well, one of which will address the need for an audit and logging functions with Netcare and other electronic health records, and we support that very much. We believe that all EHR systems need to have audit and logging functionality so that I as an individual patient can know, if I want, who has access to my health information.

In closing, while we support many of the principles behind these amendments – that is, the need to create a legislative framework for electronic health records, the need to create a framework for health information repositories, and the intention to expand the authority of the HIA to cover all health services – we do not support the way in which some of these objectives are being met. Too much is being moved from the act to regulation, and the effect of some of the amendments removes the ability of individual Albertans to control the collection, use, and disclosure of their health information. In sum, it's our view that the balance has been shifted inappropriately away from individual privacy and control.

You have our written submission, which expands on these and other points. I'd be happy now to take your questions. I want to thank you again, Mr. Horne and other members, for giving us this opportunity.

The Chair: Thank you very much, Dr. Theman. I'm sure we have a number of questions for you.

We'll begin with Mr. Fawcett.

Mr. Fawcett: Yes. Thank you, Mr. Chair. You talked about secondary users. Can you give me an example – I know you mentioned insurers or employers – of how they might get access to such information?

Dr. Theman: I'm sorry. I'm not sure I understand the question. Is the question how they might get access to such information?

Mr. Fawcett: Yeah.

Dr. Theman: Well, normally they request it of the patient or the provider, and normally the provider will seek consent from the patient in order to provide that information. That's the normal route. The question is: are there adequate safeguards around Netcare and other electronic health records to ensure that that's the only route by which insurance companies or employers or such may be able to get that information?

Mr. Fawcett: To me that seems like it would just be a basic premise of the electronic health record, but I guess I'm not sure. Maybe it's not.

The Chair: Thank you.

Mr. Quest: I'm just going back to your concern about people not having control over this information. I have no idea what the legalities would be, but would you be okay with it if every individual at the beginning of this program perhaps could sign a waiver or something of that nature, some documentation allowing this information to be collected from that day forward?

Dr. Theman: Absolutely. That goes way beyond what is currently required. I'm not a lawyer. My understanding is that in previous amendments it was considered that seeking consent specifically for any individual to have their information put into Netcare or other electronic health records was deemed unnecessary and probably just an unreasonable burden. From an administrative perspective I'm sure physicians as custodians would have a hard time with that, you know, explaining to every patient: "So here's the information about you that's currently in Netcare. Do you give your specific consent?"

The current provisions within HIA at least provide that any time disclosure happens, it must be logged. So if I as a patient am concerned about who has looked at my information, that should be

accessible to me. It also says that a custodian must consider the expressed wishes – it's not specific consent but at least the wishes – of a patient before, you know, posting information. It doesn't say that you have to comply with that request, but at least you have to consider that. When you change the definition of putting information into Netcare from disclosure to use, you take away those safeguards, and that's the point the Information and Privacy Commissioner has made much more eloquently than I can.

The Chair: Okay.
Ms Pastoor.

9:50

Ms Pastoor: Thank you very much. I'd like to try to get a clarification on how this works. In my mind I don't think the average Albertan has a hope in hell of protecting anything because when you take out insurance – i.e., Blue Cross or any of them – they want to know everything about you. And if you want the insurance, you're going to reveal it because if something happens, they're going to say: "You didn't tell us, so no insurance. Tough luck." So there's a whole little circle there that people can go in and out of. In actual fact, the person in the middle, the average Albertan that's just trying to get some health care or some insurance, really has no control over that information. How does that fit in with what you're saying, that insurance companies buy and sell people's information all the time? I mean, I believe that it does.

Dr. Theman: Honestly, I don't know. I mean, you know, I think there's a huge challenge to any custodian and, certainly, physician custodians to understand the ins and outs of legislation and how it applies and what their role is to be in terms of protecting information.

In the pre-electronic world it was a little easier. When I was in practice, you sat in my office, and we talked. You provided me information, I wrote down what was important, and it sat in a record. That record was inaccessible largely unless somebody broke into my office and stole it.

So here the issue is that all of that information is posted. By example, I went to see my family doctor a couple of weeks ago for a medication refill. He uses an electronic medical record platform called eClinician that's based here. It's a Capital health product, if you like. He said: "So here's all your information. Are you okay with this being posted? There actually is a place in here we could put specific information that only you and I can unlock." And I thought: gee, that's pretty good.

Now, as it turns out, I don't have anything that I feel shouldn't be accessible to other caregivers. But I also think it should only be accessible to other people who need it to assist me in my care and that if an insurance company wanted access to that information, the physician as custodian should be saying: well, what specifically do you need? Part of the rules here is the minimum amount of information for the purpose required, and I think that's a hard concept for many custodians, certainly physicians, to get their head around: the minimum information necessary for the purpose because it may be that you don't have to provide everything about somebody.

Ms Pastoor: Yes, and I follow exactly what you're thinking. But what I'm afraid of is that you've already signed that consent form to the insurance company to say that these are all of the things that are going on. That's what they're selling anyway.

Dr. Theman: I understand.

Ms Pastoor: So now you're protecting it from a doctor that might help you, but the insurance is still selling your information. And I don't know how . . .

Dr. Theman: I agree, and I think that's one of the challenges. Even though the patient has signed a consent for that, does the patient understand? "Here is all of the information that will be provided. Is that really what you want me to do, or do you want me to be more careful and ask specifically: what information do you need for this purpose?" Because that's really what the goal of this is.

Ms Pastoor: So you feel that that should be legislated and not regulated.

Dr. Theman: Well, I think the worry about regulations is that in large part we don't know what's going to be in regulations. While, you know, regulations may require consultation, they don't have the same degree of scrutiny and public debate that amendments to legislation have.

The Chair: Thank you.
Mr. Dallas.

Mr. Dallas: Thank you, Mr. Chairman. My question relates to the discussion on balance in terms of disclosure. Given your expertise I'm wondering if you can describe for us or comment on the issues of where the withholding of information would jeopardize either the outcome for a patient or jeopardize the health of a care provider and if you feel that's it's appropriate or possible to differentiate between the types of information that would ensure a minimum standard of caregiver ability to provide appropriate care while at the same time protecting the health and welfare of those that are providing that care.

Dr. Theman: Well, an example, I suppose, would be if a patient is HIV positive and is very worried about sharing that information. If I tell my doctor I'm HIV positive, that information is going to get into the electronic health record, and I don't want that there because I have cousins who work at the Grey Nuns and, you know, they could pull up my record and find that out. So I don't tell my doctor. In the consideration of what's wrong with me, the fact that I have HIV is not a consideration because I won't reveal that information. The physician then has an inadequate database on which to consider diagnosis and treatment. You may not know what medications – well, you probably would if you pulled up the pharmaceutical information network. But, you know, there's a whole series, just kind of a cascade of effects of potential challenges in terms of diagnosis and treatment and then drug interactions and various things that could fall out of that.

Mr. Dallas: Just to supplement that. Either knowingly or perhaps more often unknowingly, the compromise is that a patient could determine to secure information that actually could very significantly undermine their own treatment and recovery from a variety of ailments.

Dr. Theman: Correct. Now, my understanding of many electronic health systems at the present time is that they provide the ability to mask certain information. Dr. Sherman in the emergency department can unmask that information if absolutely necessary, but when he does so, that is logged. If you arrive in the emergency unconscious – you can't provide consent – and, you know, in your record there's information that you think I need to know, what this person's

medications are, and that's locked information, there is an ability to unlock it, but it's also got to be logged and that information made available under the disclosure requirements. That's the kind of safeguard that I think the Privacy Commissioner is looking for and that we would consider to be a reasonable balance.

Mr. Dallas: Thank you.

The Chair: Thank you.

We have time probably for one more. Dr. Sherman.

Dr. Sherman: Thank you, Mr. Chair, and thank you, Dr. Theman. We can agree that the electronic health record and the Netcare have significantly improved our ability to communicate as health workers, to communicate, gather information to make the right decisions on the patient. I would say as a health care worker that it has helped to improve care. Currently my understanding is – I may be wrong – that the security is mainly a complaint-based system. Currently if I were to look at my own health record, I would probably get a call from the people up above saying: what are you doing? So it's either complaint based – somebody suspects that somebody is looking at your data – or if you look at your own.

I guess the question I have to ask you is: if the data is more accessible and your private life is more accessible and open to the whole world, to a larger number of health care providers who have access – and God knows what they have access to. I guess, for example, we could say one of our members on this committee has an STD, and one has a mental illness, and one has a family member – they've disclosed these personal details to their physicians. Our hope with the discussion here is to improve care. Is it conceivable that patients actually may not seek care if they have these issues, such as a mental illness or an STD, syphilis or HIV?

Dr. Theman: Yes. Absolutely. My guess is that it's probably a relatively small number of people who would be concerned about that, and it would probably be very sensitive kinds of health issues such as you described. But even so, it is entirely possible that there are people, patients, who would not disclose their information. There may well be physicians who would be just as concerned about disclosing that information to an electronic record because of the secondary effects. I mean, I can tell you that I've had conversations with physicians, some who have phoned me and said: I don't care what you do to me; I'm never putting anything on an electronic record because I don't trust the security of it. You know, if I'm a psychiatrist, my patients all have mental illnesses of one sort or another. So I think we do have to have some safeguards in order to make not only patients but custodians feel that this is safe.

10:00

I'm with you in the belief that electronic health records have the potential to improve patient care. I think the aggregate information that we gather is essential to understanding how well the health system is working, so I think we need to gather accurate information and use it wisely, but we also need to safeguard patients' privacy.

Dr. Sherman: Thank you.

The Chair: Thank you. Well, Dr. Theman, I'd like to thank you very much for appearing before the committee, both for your presentation and for your written brief. It's going to be very useful to us in our deliberations. Thank you for taking the time.

Dr. Theman: Thank you, committee, and thank you, Mr. Horne.

The Chair: Members, we're going to take a short break here. We'll reconvene at 10:15 with the next presentation. Thank you.

[The committee adjourned from 10:01 a.m. to 10:19 a.m.]

The Chair: Colleagues, our next presenter is Mr. Greg Eberhart. He is the registrar of the Alberta College of Pharmacists. Mr. Eberhart, thank you very much for appearing before the committee. We're delighted to have you here.

We'll just begin by asking the members of the committee to introduce themselves, beginning with the deputy chair.

Ms Pastoor: Thank you. Deputy Chair Bridget Pastoor, Lethbridge-East.

Dr. Sherman: Raj Sherman, Edmonton-Meadowlark.

Mr. Dallas: Cal Dallas, Red Deer-South.

Mr. Vandermeer: Tony Vandermeer, Edmonton-Beverly-Clareview.

Ms Notley: Rachel Notley, Edmonton-Strathcona.

Mr. Quest: Dave Quest, Strathcona.

Mr. Fawcett: Kyle Fawcett, Calgary-North Hill.

The Chair: Fred Horne, MLA for Edmonton-Rutherford and committee chair.

Mr. Eberhart, I understand that you have a written submission, which has just been distributed to the members. What we're doing with the presentations is we're asking you to spend up to 15 minutes on some formal comments to the committee and to leave us, if you would, please, at least 15 minutes to ask some questions of you and engage in some discussion. Please proceed.

Alberta College of Pharmacists

Mr. Eberhart: Thank you, Mr. Horne, and thank you, committee members, for this opportunity to participate in the consultation and to contribute to the evolution of Bill 52 and privacy legislation in Alberta. Again, I am Greg Eberhart. I'm the registrar of the Alberta College of Pharmacists.

Our college, like the College of Physicians and Surgeons, has a legislative mandate, established under the Health Professions Act, where we govern the profession of pharmacy. We also license pharmacies in Alberta under the Pharmacy and Drug Act. We, too, our members and pharmacies, have been custodians under the existing Health Information Act since its inception, so we have had experience in dealing with members of the public and dealing with the evolution of the policy and the many trials that we've had with that over the years.

As a preamble to my comments I'd just like to observe that we in the health system do work in a knowledge-based industry. It's a knowledge-based service which is highly dependent on the availability of complete, comprehensive, quality information in a timely manner, and those elements are becoming even more important today as we have a shortage of health professionals. We have patients who are accessing the health system at different points, at different times. They're exercising their choice as to what services they want and from whom they want them. It's creating quite different relationships within the health system, where we have

health professionals working horizontally with one another rather than within a vertically integrated system. Through that, the whole issue of information sharing and the ability for clinicians, whoever they may be, to have access to the information that they need to make informed decisions in a timely manner is more important than ever.

While our profession advocated for the integration of records between pharmacies as early as the 1970s, we find ourselves today still awaiting the full evolution of the electronic health record to achieve the ends that we have believed in for a long time.

I'd like to emphasize that I believe that one of the challenges we have faced in the area of public policy and in the area of public trust is that there are two distinct purposes for health information. The first and the primary purpose of that is to care for patients. I think that with many of the issues that I've heard previous presenters speak to and that they will speak to, the public does not have a concern from our perspective with respect to the sharing of information amongst their care providers to make sure that quality decisions, informed decisions can be made in a timely manner. There are questions, however, about the secondary use of the information. Unfortunately, since the inception of the Health Information Act some seven years ago and even today those two issues, those two purposes, become intertwined with one another, which creates confusion.

I would also observe, when we talk about patient empowerment, that the approach that we are taking in Alberta and at other points in Canada is somewhat different than in Europe. In Europe in the evolution of the electronic health records we are now truly talking about the empowerment of patients, where they own the records. They have access to the records. They have access to the logs to understand who has accessed the record. They can contribute to the record. They are a full participant in the policy and the evolution of that electronic arena. That's quite different than what we've had in Alberta, where, as somebody suggested earlier, most of our citizens are probably naive to these discussions and never really contemplate it until they access health services, wherever that might be in the system.

Now, with that preamble I, too, would emphasize that there are many improvements that have been brought forward through the amendments proposed in Bill 52. We do support and are pleased that government has taken the initiative to expand the scope and the reach of the Health Information Act to include all health providers regardless of the manner in which they're paid. I think you'll see in our comments that the next challenge will be the processes that are used to identify who becomes a custodian at what time.

We are also encouraged that there is an amendment that now makes that health provider information part of the patient information. We would submit that the protection of provider information is best taken care of through complementary legislation that exists in Alberta, again to protect the rights of those providers.

10:25

Now to speak to some of the areas where we have concerns. Again, conceptually we agree with many of the principles that have been brought forward in the legislation. The manner in which some of these are proposed to be achieved does leave questions in our minds. The first area that we'd like to express some concern about is proposed amendment 11(b), which speaks to the repealing of section 46(5) of the act and the requirement of the minister to complete a privacy impact assessment.

Privacy impact assessments are tools that are used prospectively to evaluate changes in technology, changes in uses with respect to health information. This is an important procedure, again, to understand the security measures that are in place and the potential impact on the privacy of the personal information of individuals. Section 46(5) addresses that arena where health information is still spoken to in the context of collection, use, and disclosure. We would emphasize that in that arena, from our perspective, any time that information is collected, used, and disclosed, it's very important that there be a mechanism for logging and that there be privacy impact assessments in place, particularly if secondary uses are to occur.

We would go further to observe, akin to our colleagues from the College of Physicians and Surgeons, that the amendments in part 5.1 respecting the electronic health record do not contemplate a privacy impact assessment. We would emphasize again the impact of a privacy impact assessment prospectively prior to implementing or changing any technology that is in place or the use of information that is submitted for the purposes of being managed by that technology.

Secondly, I'd like to speak to the use of personal information by colleges such as ours for quality assurance and quality improvement purposes. As mentioned earlier, we work and we serve in a knowledge-based service industry to care for the health and the well-being of the citizens of Alberta. The collection of information and the use of information by individual practitioners is important. The government has granted us a mandate to take responsibility for the ethical, responsible, and accountable conduct of our members. In the interest of quality improvement it's important that we understand some of the trends and, in identifying those trends, that we have the ability to identify when and how to intervene in order to improve both prescribing and dispensing events.

We began journeys in this area back in the 1980s, again in collaboration and in partnership with the College of Physicians and Surgeons of Alberta, the faculty of pharmacy at the University of Alberta, and the faculty of medicine at the University of Alberta. Over a 20-year period we have consistently been challenged by the availability of and access to appropriate information to assist in the type of analysis that I described.

I think Dr. Theman in his presentation presented well both the need and the opportunities that we as colleges have to contribute more effectively to the appropriate use of medications, providing that access to this information is available to us. We would recommend that section 35 of the HIA, which proposes an amendment to allow custodians to disclose information to colleges for the purposes of submitting a complaint, be further amended to authorize health professional bodies access to personal health information for the purpose of administering quality assurance and quality improvement programs that address the performance of their registrants. Access should be provided from custodians and from health information repositories proposed in part 6.1 of the bill.

That leads me to our next comments, with respect to the health information repositories. We support the intent and the principle of health information repositories. However, the proposed amendments are vague in their presentation as to what these are and what they are not. The proposed legislation provides broad latitude for further definition with respect to the roles, duties, powers, and functions of repositories in the regulations. However, the proposed amendments are silent about any restrictions on health information repositories. As a result of that, we would leave you with three recommendations.

First, consistent with previous recommendations, that a privacy impact assessment be required in advance of any health information repository being established and that this be updated at any time when there is a change to the information systems being used to manage the repository or when there is any change in the policies respecting the use of the information stored in the repository unless previously authorized by an ethics review board.

Number two, that health professional bodies be provided access to information stored within repositories, this access to facilitate quality assurance and quality improvement programs consistent with their mandate granted under the Health Professions Act. Further, access to personal health information by health professional bodies should be separate from, not pursuant to, the requirements of individuals conducting research as defined in the act. Again, the emphasis here is that the role, the mandate, and the purpose of the colleges are quite different from the academic research proposed through the definition in the act.

Third, that restrictions be made respecting entities that may qualify as a repository and the purposes for which personal or aggregate information retained within the repository may be used. Specifically, a repository operator must not be permitted to use the information directly or indirectly for commercial purposes. I believe that that observation, again, aligns with some of those provided by Dr. Theman.

A fourth area of comment would be with respect to the definition of custodian. Again, we are strong proponents of the broader scope of the act. We note that the identification of custodians will be established and achieved through regulations. But we would like to observe that it's very important that we consider the practice relationships and the direct consequential relationships between different health professionals and to ensure that if one health professional is a custodian, the other one also be considered a custodian. Said a different way, we would encourage the government to consult with health professional bodies to ensure that we understand those professional relationships prior to determining who is a custodian, to ensure that the regulations do not create an artificial impediment to nurturing the partnerships that we are pursuing and encouraging within the health system.

Fifth, proposed amendment 2(iv), which is an amendment to the information about health service providers to be included as part of diagnostic, treatment, and care information. The proposed amendment appropriately addresses health service provider information as patient information. Our observation in reviewing the list of information that is identified is that it is slightly different than the list of registration information that is collected by health professional bodies through the Health Professions Act. To that end, we would recommend that the list of information proposed in amendment 2(iv) be reviewed and further amended to be consistent with registration information collected by health professional bodies under the HPA. Again, we work as a system. We as colleges are often called upon by government, different parts of government, for information from our registry. I think that this could work much more smoothly if we ensured that the various pieces of legislation were aligned with one another and consistent with one another.

Our last recommendation would be consistent with another which you've heard earlier this morning, and that is with respect to the logging of access to personal information in the context of the electronic health record. We recognize that there is a provision for electronic logging in the first part of the act, where we are not working in the electronic arena. It provides that there needs to be documentation any time that information is disclosed, but it also provides an avenue where that documentation can occur electronically subject to the electronic technology having the ability to capture specific information.

We would again submit that in the context of the electronic health record it is equally important that a logging mechanism be in place to ensure that there is clarity as to who has used the information, at what time, and for what purpose. Therefore, we would recommend that the electronic health record be further amended to include an electronic logging requirement for the purpose of identifying who has used the personal information stored in the EHR, when it was used, and the information that it was used for.

10:35

That concludes my comments, Mr. Horne. I again thank the committee and hope that the observations and recommendations that we've shared today can contribute to further dialogue and enhance the legislation as proposed. Equally so, knowing that regulations will be substantive to operationalizing this legislation, we would look forward to being consulted and involved in the development of those regulations because there's so much more clarity that is to be achieved through them.

The Chair: Thank you very much, Mr. Eberhart. Thank you for a very detailed and thorough presentation and for leaving it with us in written form as well. It's very helpful.

I expect we may have a few questions for you.

Mr. Dallas: Mr. Eberhart, with respect to item 5, you speak about the alignment of information that your professional body collects in comparison to information that would be on the electronic health record. I wonder if you could give us some examples of that and what the compelling reason would be that the alignment would be with respect to the information that's in the Alberta Health Services database as opposed to your professional body database.

Mr. Eberhart: This is a little bit of a long journey. There are lots of permutations associated with this that bring it to mind. Again, the Health Professions Act identifies personal information that must be collected for the purposes of registration. It also identifies the information that is publicly available. We have been involved in some consultations with Health and Wellness around other areas to support the provider registry. The provider registry is a subcomponent of the electronic health record which identifies the health providers who are participating in the electronic health record. Recently there have been discussions about some regulation amendments as to what type of information might be contemplated through regulation. For some of those recommendations we've had to ask: why do you need that information? There's already something that is prescribed through the Health Professions Act, and by providing this additional information, what additional value is it going to provide to the system?

We've also been working with Health and Wellness in another arena around prac IDs, which are numbers that have typically been used, I believe, in the billing arena. Prac IDs are important to support the working relationships between health professionals. Again, when involved in that discussion, the information about our members that's been requested has been a little bit different.

Now we come into another legislated arena. We're looking at a separate piece of legislation but, we believe, complementary legislation, and we'd just like to emphasize that we believe that there's opportunity and that it would be prudent to try and address things from the same mindset.

In looking to the Health Information Act, the one small piece that I observed here was municipality. In the case of colleges, we do not collect information about municipalities. It's more the principle as compared to the absolute. When we develop provincial legislation, we should try and understand other pieces of legislation and, we would submit, endeavour to align them to the best of our ability if possible.

The Chair: Others? Dr. Sherman.

Dr. Sherman: Thank you, Mr. Chairman. Thank you, Mr. Eberhart. As health care providers it's important for us to know which physician a patient has seen when they come to us, how many physicians, what drugs they're on. Also, between the pharmacies: patients go to different pharmacies as well as different physicians, so it's important to know what prescriptions they are on. Many of our patients are elderly, and they don't know what they've taken. It's very important with the electronic health record that we as health care professionals who collaboratively look after the patients have the ability to communicate, so this is a very important piece of legislation. In order for that communication to happen, privacy is very important. My questions are: do the pharmaceutical companies have access to your databases on physician prescribing habits, and do they target their interventions in promoting certain drugs to that? What aspect of the information on your databases if they have access do they have access to?

Mr. Eberhart: They do not have access to any databases that our college administers. Our college doesn't administer any databases with respect to drug therapy.

There are pharmaceutical manufacturers that do procure information. This is second-hand insight – okay? – because I've never been involved in it. It's second-hand information. I understand that the industry can purchase information through data providers. Dr. Theman identified one of those as being IMS. My understanding is that IMS does procure information about drugs from drug wholesales. I also understand that IMS may procure some nonidentifiable patient information from some pharmacies.

Dr. Sherman: Okay. In moving forward with this, I understand that the college itself doesn't have access, but for the individual pharmacies the challenge is that one of the biggest rising costs in health care to the patient and to governments is drug costs, as we know. In the figures I've heard, 20 per cent to 30 per cent of the newest drugs are usually put on the market before they ought to be, but they're often withdrawn from the market. These are the most expensive drugs. We've heard an example recently of a certain anti-inflammatory. With the ability for them to mine physician behaviour data on a mass scale, what may be the implications of drug costs and perhaps 20 per cent, 30 per cent of the time inappropriate drugs being overly prescribed?

Mr. Eberhart: I think I have two responses for you, Dr. Sherman. One, our college is not a proponent of that type of activity. As a matter of fact, that's why our college has been a proponent of the evolution of the pharmacy information network and the need to have a safe haven where there is comprehensive information available to assist us in making informed decisions.

The second part of that is that the issues around drug use and the marketing behaviour of manufacturers is particularly complex. We have had discussions with the department that there is an opportunity to address this through some of the forthcoming legislation around the provincial pharmaceutical strategy. My understanding is that that legislation is going to have some elements around governance. My understanding is that it may have some elements around the pharmaceutical industry. We would submit that if we are really committed to the sustainability of our health system and if we're really committed to the appropriate use of drugs, within that legislation we will find some statements that address behavioural changes at the manufacturers' level, at the professionals' level, and at the patients' level.

I think a corollary to your submission would be physician samples. They're just as much of the equation as anything else that we're discussing today.

Dr. Sherman: Thank you.

The Chair: Other questions?

I had one other question, Mr. Eberhart. I just wondered if you could comment about trying to put this legislation in the context of where the development of the provincial electronic health record currently stands. In a fully integrated electronic health record the local electronic medical records of individual physicians, for example, or other health care providers, depending on the legislation in effect, would be directly connected to a province-wide or a jurisdiction-wide system of some kind.

In addition to that, at the patient end of the spectrum patients in many jurisdictions have access to a portal that's designed for them that allows them to view information such as who has accessed their health information, under what circumstances. It also supports other initiatives aimed at patient education and management of chronic disease and so on.

I guess my question is: given that Alberta's system is moving in that direction but has not yet arrived, assuming we were at that end state, would any of the concerns that you've outlined today be not critical, or would they not apply?

10:45

Mr. Eberhart: I think all of the recommendations that we've provided today still apply. Regardless of the patient awareness, the patient engagement, the privacy impact assessments in and around the systems and the use of the information continue to be important. The questions that we've posed and the uncertainties around the data repositories, although we agree with them in principle and we will look for the definition within regulations, continue to be an important discussion. The ability for colleges such as ours and the College of Physicians and Surgeons independently and working together, because we have a mutual interest around the appropriate use of medications, to access information through new programs that address the performance of our members proactively to try to achieve quality, to prevent adverse events, and to minimize the possibility of complaints is something that would still be there.

The opportunity that you described, Fred, is one of further empowering the individuals, and I think that we do have a long way to go to educate Albertans and to get them actively involved in the electronic health record and as active participants in their own care.

The Chair: I guess if I could just elaborate a bit. For example, on the issue of expressed wish by the patient to keep certain information confidential, in a fully integrated electronic health record the system would have the capability, presumably, for providers to have that discussion with patients, consider their request, and then enter into the system, in which all other custodians could put effect to the patient's wishes communicated on a particular point. Equally, a patient wishing to remove a restriction to access to that information would be able to instruct their provider accordingly and, again, in real time have that removal take effect from the perspective of all other users of the system. I guess the question I'm trying to ask is: as you understand the design of the provincial electronic health record now and given the input that I know your college and others have had into that design, do you see that particular concern being alleviated as we move toward completion of our provincial EHR?

Mr. Eberhart: A couple of observations first, Mr. Horne. One, you may be aware that pharmacists in Alberta were mandated as of about 18 months ago to upload all dispensing events into the electronic health record. That was established through regulation of the minister. The question that comes forward in this legislation is that,

again, it provides that authority for the minister to require health providers to upload information. I think the question, the uncertainty is: what is that information going to be? You've identified the electronic medical record. Equally so in pharmacies there will be electronic patient records. It would not be appropriate for all of the information on those records to be submitted. Today there is a working group, a shared health record working group, that is having discussions about what information from electronic medical records should be uploaded into the electronic health record.

The real question is around the uncertainty as to what might be required by the minister and what issues or drivers are going to motivate change by any minister to require some other piece of information. How far does that go, and what are the controls around it?

The analysis that you provided. In an open arena, while everybody would be participating, I don't see anything in the legislation that talks about, yes, the patient agreeing that their information be uploaded or the patient not wishing to have their information uploaded. I would read it the other way, that under part 5.1 that authority, that decision lies in the hands of the minister to determine what information needs to be provided to the electronic health record by any health services provider.

The Chair: Thank you very much.

We have time for one last question. I had Mr. Fawcett next.

Mr. Fawcett: Thank you, Mr. Chair. You made a comment right at the beginning of your presentation about some of the systems used in Europe and how they have sort of gone above and beyond maybe where we're at in that the patient is very much the owner of the record and has access to a lot more, I guess, tools to ensure that their privacy is being respected as well as their health record is up to date and being used in a manner that's effective for their care.

This is a no different discussion, I guess, in that people now are so used to doing things electronically. Another area of sensitive information is, obviously, financial information. People seem very comfortable doing online banking and transferring funds electronically, that sort of thing, but I think there's actually a comfort level out there by people that might not be appropriate. There are some things that people should know when they're doing their online banking or that sort of thing. How do you see where we're at right now and where we could be taking this as far as really engaging the individuals at a patient level to make sure that they're very much aware of sort of the risks that they're exposed to as well as the benefits and how they can take advantage of those benefits when it comes to the electronic health record?

Mr. Eberhart: I think the key word is education, and I think that that education needs to be led by the department with individual Albertans and groups of Albertans. I think that the education needs to be proactive. We've been discussing this far too long, so we all understand the importance and the value of the electronic health record. It's important that patients understand what that is, what the opportunities for improved care and timely care are within that record. Anecdotally I can suggest to you that, you know, there are many patients that already expect that information between pharmacies is shared, which is not the truth, but they expect that it is. Again, where there is potential risk, I think it's important that we educate the public about what steps we've taken through public policy or through other solutions or actions that they might take, again, to mitigate potential risk.

I think core to this discussion goes back to my preamble. I think this is quite a different discussion when we're talking about the electronic health record and the primary use of that information by health professionals for the purpose of accommodating care as compared to the next step, where we talk about secondary uses and the uncertainty about what those secondary uses are going to be and who is going to have access to that information for secondary uses. That's a confounding component in the journey that we've been on for the past 10 years.

The Chair: Thank you very much, Mr. Eberhart, on behalf of the committee. We appreciate, again, your appearance today and the information you provided as well as the written brief.

Mr. Eberhart: Thank you.

The Chair: We'll pause for just about one minute while we shift seats at the other end of the table, and then we'll continue.

10:55

We'll come back to order, please. I'd like to welcome Dr. Tom Marrie, dean of the Faculty of Medicine and Dentistry at the University of Alberta. Dr. Marrie, thank you very much for accepting our invitation to appear before the committee.

Just before we proceed, I'd like to ask each member of the committee to introduce himself or herself.

Ms Pastoor: Yes. Deputy Chair Bridget Pastoor, Lethbridge-East.

Dr. Sherman: Raj Sherman, Edmonton-Meadowlark.

Mr. Dallas: Cal Dallas, MLA, Red Deer-South.

Mr. Vandermeer: Tony Vandermeer, Edmonton-Beverly-Clareview.

Mr. Bhardwaj: Naresh Bhardwaj, Edmonton-Ellerslie.

Ms Notley: Rachel Notley, Edmonton-Strathcona.

Mr. Quest: Dave Quest, the other Strathcona.

Mr. Fawcett: Kyle Fawcett, MLA, Calgary-North Hill.

The Chair: I'm Fred Horne, MLA for Edmonton-Rutherford and chair of the committee.

Dr. Marrie, we have approximately half an hour here. We'd appreciate if you would take up to 15 minutes for your remarks and leave us about the same amount of time for some questions and to engage in some dialogue with you. Please proceed when you're ready.

Faculty of Medicine and Dentistry, University of Alberta

Dr. Marrie: Mr. Chair, thank you, and thank you for the opportunity to present to your committee today.

I'm going to focus on the elements in the amendments to the act which are necessary to facilitate health services research. As a practising physician I have the utmost respect and concern for the protection of patient information. I've no doubt that others are going to present on those elements in the amendments, so I'm not going to spend more than a passing reference on those, but it doesn't in any way reflect that I am not concerned about those elements.

Let me introduce you to health services research and what the benefits of such an activity or activities are. The Romanow report, entitled Building on Values: The Future of Health Care in Canada,

mandated that Canadian health services researchers monitor the health system to assist and inform health care policy-makers and decision-makers. Assessing performance and providing feedback are vital elements to improving the quality of health care. Health care services research examines how people obtain access to health care, how much it costs, and what happens to them as a result of that care. Thus, the main goals of health services research are to identify the most effective ways to organize, manage, finance, and deliver high-quality care, reduce medical errors, and improve patient safety.

You can't do this kind of research without timely access to high-quality data. Such data are necessary to objectively measure the performance of a health care system, identify and verify any problems that exist, measure the impact of changes in health care policy, and identify opportunities for further improvement. It's really important that that information be available not only to individuals within government so they can assess their own performance but also, in fact, to researchers who are independent from government to perform that type of assessment.

A number of the amendments that are being made to the Health Information Act appear to assist researchers in being able to carry out this function. One of the most important changes is the provision for data repositories, namely health information repositories. That's the collection of the information that's collected on all of us all of the time.

Drawing on the experience of other jurisdictions, data repositories commonly identify patient information so you can identify individuals, or it can be deidentified through a variety of mechanisms. Some data repositories contain both types of information. Such repositories allow rapid access to the type of information that we need to perform the research functions that I outlined a few minutes ago. Currently health services research in Alberta is hampered by the obstacles that are there in gaining access to these data. With respect to health information repositories in Bill 52, that you propose, I note that there's a high degree of deference to regulations. It would certainly be nice to know what these regulations are, and I don't know whether we'll see those before the bill becomes law or after you have finished your hearings.

On occasion it is very important to be able to link an individual's patient information to multiple record sources such as vital statistics, emergency department health records, pharmacare, and so on. Now, there are safeguards to handling that information, and all the research that we do has to go through intense scrutiny by our health research ethics board. We can in fact submit information that we've collected through informed consent from patients, then get it matched in the data repository and get back information in an encrypted form that would allow us to do the research.

This stuff probably sounds meaningless without trying to put it in perspective. I've copied two graphs from my own research, and I'd like you to pick up the one that's entitled In-Patient Mortality Curves by Age. I'll give you a bit of background to this to show you the power of being able to carry out this health services research. I'm an infectious disease physician. My research for the last 30 years has been on pneumonia. Pneumonia is often a neglected area in research, and in fact it's often the way that most of us will die even though we might have cancer, heart disease, or something else. You get pneumonia; it's the common final straw. Also, very healthy young individuals living at home in the community can get pneumonia. It's one of the causes of death for people that are otherwise totally healthy.

The first graph that you see is the in-patient mortality curves by age. We carried out a study of patients who from 2000 to 2002 came to all the hospitals in – well, it's still known as Capital health, but it's shortly to disappear by that name. We were trying to improve the quality of care for pneumonia, and we had this research approved by the health ethics committee. We collected information on roughly 4,000 patients who were admitted to hospital for treatment of pneumonia. We knew a lot about what happened to them in hospital. Then we wanted to see, well, how they have done since they've been discharged from hospital. We were able to provide the database that we had to Alberta Health and Wellness, and after going through all the safeguards that are in place to protect the privacy of that information, they were able to link it with vital stats data.

If you look at this graph, it shows the cumulative survival according to individuals in three age categories. The blue are those under 45, the green 45 to 64, and I'm not quite sure what that colour is, but it's greater than 65. The mean follow-up on these individuals was 3.5 years from the time that they were first seen. For some of them it was up to five years. That was done for a very small amount of money. The initial investment was quite large – the grant I had was over a million dollars – but now we were able to do the linkage for a couple of thousand dollars. What this shows is a startling finding. The blue line, so you're under 45 and you have pneumonia – most people under 45 are healthy, not everybody, but there's still a significant long-term mortality. If you look at this, about 18 per cent of these individuals were dead within a mean time of 3.5 years. That was not known previously. You don't think of pneumonia as a bad disease. If you make it out of hospital alive, you figure you're okay at that age. The question is: why? At this stage I don't know why.

11:05

The second one is on the same database but now looking at the people that were sent home from emergency or were deemed well enough to go home. It was roughly around the same amount of patients, a few more, a little over 5,000 individuals. Most patients that come to emergency get the oxygen level measured in their blood with a very simple test. You just put a light source on your finger. It shines through your fingernail, and it tells you what percentage of blood is oxygenated. At this degree above sea level you'd like that to be 92 per cent or greater.

Some individuals were sent home with a lower oxygen concentration than 92 per cent, and look what happened to them. The mortality rate for that group was significantly higher than for the ones with good oxygenation. Now, this is accepted practice at the moment. These individuals were assessed. They looked fine. They were healthy. In fact, they did okay in the short term. For the first few days they were not doing too badly, but over time they continued to have an unacceptable death rate, so much so that 40 per cent of them were dead in this mean follow-up time. Now, this should lead, as we work through this because we actually haven't analyzed all the data, to a change in policy. Knowing this information, I would really not send somebody home who has an oxygen level that's even a little bit low.

That, I think, really portrays for you the significance of being able to have access to these kind of data. For me it's all about trying to improve the health care system, to be able to look at what we're doing.

Now, having said that, I have a few comments on the act itself. On page 4 of the bill section 2(a)(ix) amends the definition of research as set out under section 1(v) of the act. This definition is very narrow, but for the purposes for which we wish to carry out this research, the definition is in fact, I think, appropriate, and I would hope you would leave it that way.

On page 6 section 4 of the bill amends section 27(1)(d). This appears to amend what use activates the triggers for the requirement to obtain research ethics board approval. Currently the trigger is

research, and what is proposed is adding "data matching or other services to facilitate another person's research" services. It's that last few words that I don't understand. What does it mean about another person's research services? I'm unclear about what the policy intent is here. As an investigator I'm responsible for finding a principal investigator for the conduct of the research and making sure that all the safeguards are in place for using these data, so I'm worried a little bit about another person's research, and I would hope you could make clear as to what the policy intention is here.

On pages 17 to 19 the bill adds to the act several provisions regarding the Alberta electronic health record. First, section 56.1. What does an integrated electronic health record mean? I think you need to be more specific here. There are all kinds of things that could go in there. I think you need to be specific.

Secondly, section 56.4. Under this section, specifically (b)(i) and (ii), the permissible uses of information in the electronic health record differ for certain select custodians, such as the department and other authorized custodians. The permissible uses for authorized custodians do not appear to contemplate research. My question here is: does this section conflict with what otherwise custodians could do under research rules? You have to remember that I'm not a lawyer, but reading this, it seemed to me to be confusing.

As a general comment, I think that you also should consider facilitating obituary information about deceased persons. In a number of the kinds of research that we do with health research, we collect the information prospectively and then want to follow longitudinally what has happened to individuals over time, which is in these data repositories. A number of the individuals will have died. Some view that the act currently requires us to get research ethics board dispensation for consent in respect of the deceased's information or else obtain consent from the administrator of the estate, when this is clearly an impossible thing to do in most instances. The bill would benefit if it clarified whether individuals can consent to the use and disclosure of their information after they've died, but clearly they'd have to consent before they died. What we would also like is to be able to have that consented to by the research ethics board under the appropriate conditions, of course.

I know from discussing the amendments to this act with a number of my colleagues that there is concern about the amendments that relate to the electronic health record and what these changes will do to the ability of a physician to safeguard his or her patients' information. If this becomes a factor for impeding the progress of this bill, I would urge that you actually make two bills. Deal with the data repositories, and if the issues surrounding the electronic health record are so problematic that you can't resolve them at present, go back to the drawing board on that, but don't interfere with the good things in this bill that would allow what's possible for us to do the research that we think is necessary to improve the health care system.

Lastly, I would like to draw your attention to Canada Health Infoway identification of privacy and security issues that are critical to the protection of personal health information. I have no doubt you're aware of them, but I think that if these were spelled out better in the act, it would give the public the assurance that they need to know that their health care information is well protected.

Thank you again for the opportunity to present. I think I did it within the 15 minutes, at 14 and a half. I'd be glad to answer any questions you have.

The Chair: Okay. Thank you very much, Dr. Marrie. That was very helpful. Thank you for the written brief as well.

Mr. Fawcett.

Mr. Fawcett: Thank you, Mr. Chair. You mentioned that currently researchers in Alberta have been hampered by obstacles in gaining access to data. Can you give us an indication of what those obstacles are?

Dr. Marrie: Currently, because of the way the Health Information Act is written, for some types of information you can't get access at all. It used to take up to two years to get access by the time you had jumped through all the hoops. That's improved a lot over the last little while. With my own research it went very well, but it went very well for a number of reasons that probably weren't available to other researchers. When you're doing research, you get a grant. You're expected, once the funding comes, to produce in a certain time period what you said you'd do. If it takes you eight or nine months to get the information, you've already lost a lot of valuable time. The process at the moment is pretty ponderous.

The Chair: Thank you.

Ms Pastoor.

Ms Pastoor: Thank you very much, Mr. Chair. Dr. Marrie, you made an interesting comment on information about deceased persons from obituaries.

Dr. Marrie: Yeah.

Ms Pastoor: My background is long-term care, and my comment on that would be that you don't know a lot of information from an obituary because there are no autopsies done, and people aren't dying of old age. Too bad, write it off; end of story.

Dr. Marrie: Well, you're correct. One part of it – and I've studied this for some time – is that death certificates are enormously difficult to interpret. The way, in fact, they are currently written makes it impossible to know what was the primary cause of death. I've filled them out, and when I'm filling them out, I'm not clear on that. Myself and investigators in Boston and Pittsburgh were funded by NIH to study the causes of death from pneumonia. We spent two years working with death certificates, and I recognize what you say. However, there are some elements of information in there that are useful, but one has to be concerned about the validity. I think the time has come to amend death certificates in the country.

Ms Pastoor: Thank you. I'm pleased to hear that because someone might die of pneumonia, but it was because of the fall two days prior to that.

Dr. Marrie: Absolutely. You know, in another setting I'd love to debate it with you.

Ms Pastoor: Count on it.

The Chair: Thank you. Others?

Dr. Marrie, I have a question for you. I'm just wondering if you can tell us. You've certainly made the case for how the act would improve research capacity in the health system. I'm just wondering if you could describe the next stage, then. How do you take findings such as the ones you've presented here and propose changes to the health service delivery system that would help alleviate some of the findings you presented?

11:15

Dr. Marrie: It's a great question, and I'd like to thank you for it because I do have an answer. We have been working for some time

to create a health analytics unit at U of A in conjunction with the University of Calgary as well. As a province we don't do this very well. I would like to model this on the Institute for Clinical Evaluative Sciences in Ontario, which is the model. That institute currently has about 150 researchers on staff. The data repositories of health care information that have been created under a similar act in Ontario are freely available with lots of safeguards to researchers in that unit.

The Ontario government contracts with the researchers regularly for about 25 to 30 studies per year which will examine specific questions related to the delivery of health care. The researchers do the study, provide the information to government. It's public information, so you can go on the website and know exactly what the study has found. It might be mortality rates from myocardial infarction, as an example, and how that compares with such rates from other parts of the country.

About half the activities of the unit are funded that way. The other half are funded from research grants and are driven by the things that the investigators want to do. It's a synergy of contract research on the part of government, and what government is getting is an independent opinion. Individuals are trained in this science, but in no way has any government bias been built in. Sometimes they like the results, sometimes they don't, but that's the same for everything. It gives the public some reassurance about the state of their health care delivery system.

Even more importantly, if you get a finding like this and you've now got that relationship with government, then the question is: what should you do? What should the changes be? It's got to drive policy. Seeing this, once we get this analysis done, I'd say: well, in Alberta we don't send people home from emergency whose oxygen saturation is less than 90 per cent. So you'd drive policy. That to me is the exciting thing about the amendments to this act that I think will allow us to do this. The government maximizes resources. We hire these individuals in universities, and, you know, it's a synergy. That's where this should be going.

The Chair: Thank you.

Dr. Sherman.

Dr. Sherman: Thank you, Mr. Chairman. Thank you, Dr. Marrie. I think that not only is clinical work, the ability to provide clinical care, absolutely essential, but I think the ability to do evidence-based research is absolutely critical. You know, having gone through medical school 16 years ago, when you read a text, it's already half outdated with the new technologies, the new tests, the new medications. In medicine in general we were looking at: "Why are we doing things? Do we need to do things?" As a trauma physician I used to know that everyone who had a sore belly who was in an accident would go to the operating room. Now 80 per cent of the time we don't operate.

I think it's absolutely critical that those who do clinical research, especially in the academic institutions, have the ability to gather data, to make sure that we have best practices that are best for the patient as well as most cost-effective for the patient in improving the sustainability of the health system. It's also a great opportunity to actually educate in real time: everyone who graduates as a physician leaves with the latest research. When you get a patient presenting with a problem, have clinical practice guidelines on the Net for a patient with that problem, have decision-making tools and treatment protocols, anywhere from a paramedic to the nurse at triage to the doctor on the front line to a doctor in a clinic.

In order to do that, you need information. I wonder if you could comment on – currently everyone has to do a written consent – consent for information and as well on masking of information and on how much information you would need from a patient's record. For instance, physicians have a concern that all of their private data in the office will also be on the web. If you could comment on how to provide the best possible research, on how much information you will need, on whether patients' names need to be on there or whether you just need an ID number.

Dr. Marrie: If I go back to what I've presented to you with the pneumonia, these individuals I followed prospectively, collected a great deal of information with their consent. Now, though, I only need from the databases that are collected information such as repeat visits to the hospital, to the emergency room, to doctors, what drugs they were prescribed. Once that's linked in the privacy of Alberta Health and Wellness, you can strip all the identifiers and just number the individuals from 1 to 5,000. I have no need at this stage to know the identity, nor do I want to know. It becomes aggregate data.

There are other instances where you actually do need to know the identity, but those are generally carried out as prospective studies where you've presented a protocol to the individual, they've read it, and they can sign a consent. This will not be the only research that's done. You can do certain types of research with these databases. They're incredibly powerful, but they're not the only kinds of research. Notice that I label that health services research. There are lots of other kinds of research. It's well suited to this particular entity of health services research.

Dr. Sherman: Thank you.

The Chair: Thank you.

Any others? Seeing none, then, Dr. Marrie, I'd like to thank you again on behalf of the committee for appearing today. You've been of great help. We appreciate your time.

Dr. Marrie: Thank you, Mr. Chair. Thank you, members of the committee.

The Chair: Thank you.

Just before we adjourn, I wonder if members would give me about 30 seconds to confer with the clerk on something, and then I promise we'll wrap up.

Thank you. In terms of other business, members, does anyone have any other business they'd like to raise?

Mr. Quest: Mr. Chair, I missed part of the first meeting. I understand there was a technical briefing. It just seems that something that's consistent here is that everybody supports the idea but has different opinions on who should have access and how it should be protected. I have a few technical questions with respect to how this information can be secured and how much control individuals can have of their own information and access and so on. Was that all covered in the first meeting?

The Chair: There was a technical briefing at the first meeting. The information, the hard copy that was provided here, is on the committee's internal website. We have one representative from the Department of Health and Wellness with us today, and there's certainly nothing to stop the committee from asking for an additional technical briefing from the department. For the next meeting we have a full slate of presentations already scheduled, but we can certainly do that at any time.

Mr. Quest: Well, I'm just wondering if any other members of the committee would see some value in that. Again, it just keeps coming back, in my own mind anyway, to what we can or can't do technically to protect this. This is the circle that we seem to be in. It might be valuable later on.

The Chair: Mr. Fawcett on this point.

Mr. Fawcett: Yeah. Thank you, Mr. Chair. I would agree with Mr. Quest. It's kind of a chicken-and-egg thing. I guess we have had the technical briefing, but particularly from some of the presentations there might be some more questions that we might like to ask the department. It might be wise to go through our presentations and then have the department here again for some additional questions.

11:25

The Chair: Is that agreed? I'll undertake to arrange that. I think what we're talking about here is an ongoing presence of the department similar to our review of the last bill, and we need to make sure that we have all the necessary perspectives. The technical as it pertains to the electronic health record is an example, the legal as it pertains to the act, and perhaps the policy perspective as well. I'll undertake that on behalf of the committee if that's acceptable.

The other thing I would like to suggest to the committee. We're now beginning to collect a number of briefings on the bill that are supplementing the oral presentations here. I'd like to suggest that we immediately adopt the practice of posting these briefings on the external website of the committee after they have been presented here in our proceedings so that they are available to members of the public who may wish to avail themselves of that information. Just for the record I'm going to ask for a motion, then, in that regard. Mr. Dallas. The motion is that

> written briefings presented to the committee be posted to the external, or public, website of the committee immediately following the committee meeting at which the material was presented.

Okay. No discussion? Those in favour? Opposed, if any? That's carried. Thank you very much.

Madam Clerk, have I missed anything? Our next meeting is Wednesday, February 4, at 8:30. We have a longer slate of presentations that day. Again, we'll use all the time we need, but we won't use any time that's not required as well.

A motion for adjournment, please. Mr. Fawcett. Thank you. Those in favour? We're adjourned. Thank you.

[The committee adjourned at 11:27 a.m.]

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